



PARTICIPANT EXPERIENCE SURVEY (BRAIN INJURY)

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*Developed by
The MEDSTAT Group, Inc*



*for the
Centers for Medicare and Medicaid Services*



Survey Instructions

- Text that should be read to the respondent is in mixed case (upper and lower). Text all CAPS should not be read to the respondent.
- Please answer every question by checking **one** box, ☒ unless instructed to "Check all that apply," in which case multiple boxes may be checked.
- Do not leave any questions blank. If the respondent does not answer an item, check the box for "No Response."
- Record **only** responses provided by the respondent, and/or verify with the respondent any responses given by other people.
- Some questions require you to write in the respondent's answer, like the example below. Please record the respondent's verbatim response as best you can.

43. What do you do during the day? (SPECIFY)

- Some questions are skipped over in this survey. When this is necessary, an arrow directs you to the next question to be asked, like the example below.

1	<input type="checkbox"/>	YES
2	<input type="checkbox"/>	NO →Skip to Q.15
96	<input type="checkbox"/>	UNSURE →Skip to Q.17
97	<input type="checkbox"/>	UNCLEAR RESPONSE →Skip to Q.17
98	<input type="checkbox"/>	NO RESPONSE →Skip to Q.17

- If there is **no** arrow next to a response category, like the "YES" response above, please continue with the very next item in the sequence.
- Some items have instruction boxes, like the example below. These boxes are intended to provide you with additional information or instructions. Do not read these to the respondent.

<i>Refer to the face sheet for the case manager's name.</i>	1	<input type="checkbox"/>	NAMES CASE MANAGER
	2	<input checked="" type="checkbox"/>	DOES NOT NAME CASE MANAGER
	97	<input type="checkbox"/>	UNCLEAR RESPONSE
	98	<input type="checkbox"/>	NO RESPONSE
	99	<input type="checkbox"/>	I DON'T REMEMBER



PARTICIPANT EXPERIENCE SURVEY – BRAIN INJURY

Hello, my name is _____ and I am from _____. How are you today? Thank you again for letting me come talk with you. I am very interested in hearing about your life and how satisfied you are with the help you get from the people paid to help you. This information will be used to decide if this program is doing a good job. If you have any questions, please stop me and ask me. Also, please let me know if a question does not make sense or if you would like me to repeat it.

Some people, as a result of their injury, may not be able to remember the answer to some of these questions, or to answer them quickly. If you do not remember the answer to a question I ask, please tell me. This is not a test - “I don’t remember” could be the best answer. Also, we can take as much time as you would like to go through the survey. I am in no hurry.

Do you have any questions before we start? Are you ready to begin?

I. Program Supports

The first questions I'd like to ask you have to do with where you live.

1. Do you like where you live?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE

2. Who choose (this/that) place to live?

- 1 ☐ I DID OR I HELPED TO CHOOSE
- 2 ☐ SOMEONE ELSE DID
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

3. Who do you live with?

(CHECK CATEGORY)

- 1 ☐ HOUSEMATES
- 2 ☐ FAMILY
- 3 ☐ ALONE →Skip to Q.6
- 4 ☐ SPOUSE/GIRLFRIEND/BOYFRIEND→Skip to Q.8
- 96 ☐ UNSURE→Skip to Q.8
- 97 ☐ UNCLEAR RESPONSE→Skip to Q.8
- 98 ☐ NO RESPONSE→Skip to Q.8
- 99 ☐ I DON'T REMEMBER→Skip to Q.8



4. If you had your choice, would you rather live alone, with your family, or with a friend?

- 1 ☐ ALONE
- 2 ☐ FAMILY
- 3 ☐ FRIEND(S)
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE

5. Do you like the people who share your home now?

- 1 ☐ YES
 - 2 ☐ NO
 - 95 ☐ NOT APPLICABLE-LIVES WITH FAMILY
 - 96 ☐ UNSURE
 - 97 ☐ UNCLEAR RESPONSE
 - 98 ☐ NO RESPONSE
- } → Skip to Q.8

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***** REMEMBER, THESE NEXT TWO QUESTIONS ARE ONLY FOR PEOPLE LIVING ALONE ****

6. Who decided you should live alone?

- 1 ☐ YOU
- 2 ☐ FAMILY
- 3 ☐ STAFF/SOMEONE ELSE
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

7. If you had your choice, would you rather live alone, with your family, or with a friend?

- 1 ☐ ALONE
- 2 ☐ FAMILY
- 3 ☐ FRIEND(S)
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE



These next few questions are about the assistance you receive from your case manager.

8. Who is your case manager? Is it _____?

Refer to the face
sheet or other
materials for the
case manager's
name.

- 1 ☐ IDENTIFIES CASE MANAGER
- 2 ☐ DOESN'T IDENTIFY CASE MANAGER
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

9. Can you talk to your case manager when you need to?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 95 ☐ NOT APPLICABLE – HAVE NOT TRIED
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

10. Does your case manager help you when you ask for something?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 95 ☐ NOT APPLICABLE – HAVE NOT ASKED
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

11. Have you ever asked for any special equipment, assistive devices, or changes to your home, which might make your life easier?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q.14
- 96 ☐ UNSURE →Skip to Q.14
- 97 ☐ UNCLEAR RESPONSE →Skip to Q.14
- 98 ☐ NO RESPONSE →Skip to Q.14
- 99 ☐ I DON'T REMEMBER→Skip to Q.14

12. What equipment or changes did you ask for? (SPECIFY)

13. Did you get the equipment or make the changes you needed?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ IN PROCESS
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER



14. Have you ever asked for additional services, such as rehabilitation, job training, or transportation, that might help you reach your personal goals?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q.17
- 96 ☐ UNSURE →Skip to Q.17
- 97 ☐ UNCLEAR RESPONSE →Skip to Q.17
- 98 ☐ NO RESPONSE →Skip to Q.17
- 99 ☐ I DON'T REMEMBER→Skip to Q.17

15. What services did you aks for? (SPECIFY)

16. Did you get the services you needed?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ IN PROCESS
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

II. Choice and Control

Now I'd like to ask you about the help you get from this program, and the choices you are able to make. Again, please let me know if you do not remember whether you had a choice about the issues we discuss.

17. Who chooses the people who are paid to help you?

*Include anyone
paid to provide
assistance in any
setting.*

- 1 ☐ I DO OR I HELP CHOOSE → Skip to Q.19
- 2 ☐ SOMEONE ELSE
- 95 ☐ NO PERSONAL CARE STAFF → Skip to Q.31
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE → Skip to Q.19
- 98 ☐ NO RESPONSE → Skip to Q.19
- 99 ☐ I DON'T REMEMBER → Skip to Q.19

18. Would you like to help choose the people who are paid to help you?

- 1 ☐ YES
- 2 ☐ NO
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE

19. Did you know you can change the people paid to help you if you want?

- 1 ☐ YES
- 2 ☐ NO
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

20. Do you tell the people paid to help you what kind of help you want?

- 1 ☐ YES →Skip to Q.22
- 2 ☐ NO
- 3 ☐ SOMETIMES →Skip to Q.22
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE →Skip to Q.22
- 98 ☐ NO RESPONSE →Skip to Q.22
- 99 ☐ I DON'T REMEMBER→Skip to Q.22

21. Would you like to tell them the kind of help you want?

- 1 ☐ YES
- 2 ☐ NO
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE

22. Do the people paid to help you do a good job helping you?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE

23. Do the people paid to help you spend all the time with you that they are supposed to?

- 1 ☐ YES
- 2 ☐ NO
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

24. If there is something wrong with the help you are getting, who do you talk with to get the problem fixed?
(CHECK ALL THAT APPLY)

- 1 ☐ NO ONE
- 2 ☐ FAMILY/FRIEND
- 3 ☐ CASE MANAGER/OTHER STAFF
- 4 ☐ OTHER (SPECIFY) _____
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

Probe,
if necessary,
to place the
response in the
appropriate
category.

25. Do you think the people paid to help you understand what it is like to have a brain injury?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE



III. Respect and Dignity

Now I would like to ask you about how you are treated by the people who are paid to help you. Again, it is important for me to know if you cannot remember the answer to a question.

26. Do the people paid to help you at home treat you respectfully?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 95 ☐ NOT APPLICABLE, NO STAFF IN HOME →Skip to Q.28
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

27. Do the people paid to help you at home listen carefully to what you ask them to do?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

28. Do the people paid to help you at work, or at a day program treat you respectfully?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 95 ☐ NOT APPLICABLE, NO STAFF OUTSIDE HOME →Skip to Q.30
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

29. Do the people paid to help you at work, or at a day program listen carefully to what you ask them to do?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

30. Do people come into your room or home when you don't want them to?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

The next few questions ask if anyone is mistreating you currently. I am only asking about your life now, not about things that may have happened in the past, but have stopped.

31. Does anyone take your things now without asking first?

Reminder:

Refer to your state's policy on reporting for any suspected incidents of abuse and neglect.

- 1 ☐ YES
- 2 ☐ NO →Skip to Q.34
- 3 ☐ SOMETIMES
- 96 ☐ UNSURE →Skip to Q.34
- 97 ☐ UNCLEAR RESPONSE →Skip to Q.34
- 98 ☐ NO RESPONSE →Skip to Q.34
- 99 ☐ I DON'T REMEMBER→Skip to Q.34

32. What happens? When? Would you like to tell someone about this? (SPECIFY)

33. Who takes your things without asking first? (CHECK ALL THAT APPLY)

Probe to place the response in the appropriate category.

- 1 ☐ STAFF AT HOME
- 2 ☐ STAFF SOMEWHERE ELSE
- 3 ☐ HOUSEMATE
- 4 ☐ FAMILY/FRIEND
- 5 ☐ OTHER (SPECIFY)
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

34. Is anyone ever mean to you now or does anyone ever yell at you?

Reminder:

Refer to your state's policy on reporting for any suspected incidents of abuse and neglect.

- 1 ☐ YES
- 2 ☐ NO →Skip to Q.37
- 3 ☐ SOMETIMES
- 96 ☐ UNSURE →Skip to Q.37
- 97 ☐ UNCLEAR RESPONSE →Skip to Q.37
- 98 ☐ NO RESPONSE →Skip to Q.37
- 99 ☐ I DON'T REMEMBER→Skip to Q.37

35. What happens? Would you like to tell someone about this? (SPECIFY)

36. Who is mean to you or yells at you? (CHECK ALL THAT APPLY)

Probe to place the response in the appropriate category.

- 1 ☐ STAFF AT HOME
- 2 ☐ STAFF SOMEWHERE ELSE
- 3 ☐ HOUSEMATE
- 4 ☐ FAMILY/FRIEND
- 5 ☐ OTHER (SPECIFY)
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

37. Does anyone ever injure you now?

Reminder:

Refer to your state's policy on reporting for any suspected incidents of abuse and neglect.

- 1 ☐ YES
- 2 ☐ NO →Skip to Q40
- 3 ☐ SOMETIMES
- 96 ☐ UNSURE →Skip to Q.40
- 97 ☐ UNCLEAR RESPONSE →Skip to Q.40
- 98 ☐ NO RESPONSE →Skip to Q.40
- 99 ☐ I DON'T REMEMBER→Skip to Q.40

38. What happens? Would you like to tell someone about this? (SPECIFY)

39. Who does this? (CHECK ALL THAT APPLY)

Probe to place the response in the appropriate category.

- 1 ☐ STAFF AT HOME
- 2 ☐ STAFF SOMEWHERE ELSE
- 3 ☐ HOUSEMATE
- 4 ☐ FAMILY/FRIEND
- 5 ☐ OTHER (SPECIFY)
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

40. Does anyone ever touch you now in a way you don't like?

Reminder:

Refer to your state's policy on reporting for any suspected incidents of abuse and neglect.

- 1 ☐ YES
- 2 ☐ NO →Skip to Q43
- 3 ☐ SOMETIMES
- 96 ☐ UNSURE →Skip to Q.43
- 97 ☐ UNCLEAR RESPONSE →Skip to Q.43
- 98 ☐ NO RESPONSE →Skip to Q.43
- 99 ☐ I DON'T REMEMBER→Skip to Q.43

41. What happens? Would you like to tell someone about this? (SPECIFY)

42. Who does this? (CHECK ALL THAT APPLY)

Probe to place the response in the appropriate category.

- 1 ☐ STAFF AT HOME
- 2 ☐ STAFF SOMEWHERE ELSE
- 3 ☐ HOUSEMATE
- 4 ☐ FAMILY/FRIEND
- 5 ☐ OTHER (SPECIFY)
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER



IV. Community Activities

Now I would like to talk with you about things you do during the day, such as go to school, work, or a day program.

43. Do you have a job or other activity you do during the day, like school or a day program?

- 1 ☐ YES
- 2 ☐ NO
- 96 ☐ UNSURE → Skip to Q.48
- 97 ☐ UNCLEAR RESPONSE → Skip to Q.48
- 98 ☐ NO RESPONSE → Skip to Q.48
- 99 ☐ I DON'T REMEMBER → Skip to Q.48

44. What do you do during the day? (SPECIFY)

BOX 1

REVIEW RESPONSE AT 44.

IF RESPONDENT HAS A FORMAL DAILY ACTIVITY, ASK Q.45.
OTHERWISE, SKIP TO Q.47.

FORMAL DAILY ACTIVITIES CAN INCLUDE PAID EMPLOYMENT,
VOLUNTEER WORK, A SHELTERED DAY PROGRAM,
SCHOOLING, OR WORK-RELATED TRAINING

*****REMEMBER, THESE NEXT TWO QUESTIONS ARE ONLY FOR PEOPLE WITH A FORMAL ACTIVITY*****

45. Do you like your (job/day program/volunteer work/other)?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE

46. Who chose the (job/day program/volunteer work/other) you go to now?

- 1 ☐ I DID OR I HELPED→Skip to Q.48
- 2 ☐ SOMEONE ELSE→Skip to Q.48
- 96 ☐ UNSURE→Skip to Q.48
- 97 ☐ UNCLEAR RESPONSE→Skip to Q.48
- 98 ☐ NO RESPONSE→Skip to Q.48
- 99 ☐ I DON'T REMEMBER→Skip to Q.48



*****REMEMBER, THIS QUESTION IS ONLY FOR PEOPLE WITH NO FORMAL ACTIVITY*****

47. Do you want to do volunteer or paid work or another activity, such as school?

- 1 ☐ YES (What? _____)
- 2 ☐ NO
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE

48. Do you always have a ride to the places you need to go, like work, shopping, or the doctor's office?

- 1 ☐ YES
- 2 ☐ NO
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

The last few questions I'd like to ask you are about things you like to do in your community.

49. Are you allowed to go out in your community without supervision when you want to?

- 1 ☐ YES→Skip to Q.51
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 96 ☐ UNSURE→Skip to Q.51
- 97 ☐ UNCLEAR RESPONSE→Skip to Q.51
- 98 ☐ NO RESPONSE→Skip to Q.51
- 99 ☐ I DON'T REMEMBER→Skip to Q.51

50. Do you know why not?

- 1 ☐ YES (Why not _____?)
- 2 ☐ NO
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER



51. Do you have a chance to do things in your community when you want to?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE

52. Can you do more for yourself now than when you first started receiving services from this program? Would you say no more, a little more, or a lot more?

- 1 ☐ NO MORE
- 2 ☐ A LITTLE MORE
- 3 ☐ A LOT MORE
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

A. ADDITIONAL COMMUNITY INTEGRATION QUESTIONS

A.1 Do you like to go shopping, such as for clothes, books, or music?

- 1 ☐ YES
- 2 ☐ NO → Skip to Q.A4
- 96 ☐ UNSURE → Skip to Q.A4
- 97 ☐ UNCLEAR RESPONSE → Skip to Q.A4
- 98 ☐ NO RESPONSE → Skip to Q.A4

A.2 Do you get to go shopping?

- 1 ☐ YES
- 2 ☐ NO → Skip to Q.A4
- 3 ☐ SOMETIMES
- 96 ☐ UNSURE → Skip to Q.A4
- 97 ☐ UNCLEAR RESPONSE → Skip to Q.A4
- 98 ☐ NO RESPONSE → Skip to Q.A4
- 99 ☐ I DON'T REMEMBER → Skip to Q.A4

A.3 Who chooses where to go shopping?

- 1 ☐ I ALWAYS DO
- 2 ☐ SOMEONE ELSE
- 3 ☐ I SOMETIMES DO
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER



A.4 Do you like to go out to eat?

- 1 ☐ YES
- 2 ☐ NO → Skip to Q.A7
- 96 ☐ UNSURE → Skip to Q. A7
- 97 ☐ UNCLEAR RESPONSE → Skip to Q. A7
- 98 ☐ NO RESPONSE → Skip to Q. A7

A.5 Do you get to go out to eat?

- 1 ☐ YES
- 2 ☐ NO → Skip to Q. A7
- 3 ☐ SOMETIMES
- 96 ☐ UNSURE → Skip to Q. A7
- 97 ☐ UNCLEAR RESPONSE → Skip to Q. A7
- 98 ☐ NO RESPONSE → Skip to Q. A7
- 99 ☐ I DON'T REMEMBER → Skip to Q.A7

A.6 Who chooses where you eat out?

- 1 ☐ I ALWAYS DO
- 2 ☐ SOMEONE ELSE
- 3 ☐ I SOMETIMES DO
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

A.7 Do you have people you like to visit with?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q.A9
- 3 ☐ SOMETIMES
- 96 ☐ UNSURE →Skip to Q.A9
- 97 ☐ UNCLEAR RESPONSE →Skip to Q.A9
- 98 ☐ NO RESPONSE →Skip to Q.A9

A.8 Can you see these people when you want?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

A.9 Do you like to go to church or other religious services?

- 1 ☐ YES
- 2 ☐ NO→Skip to Q.A11
- 96 ☐ UNSURE→Skip to Q. A11
- 97 ☐ UNCLEAR RESPONSE→Skip to Q. A11
- 98 ☐ NO RESPONSE→Skip to Q. A11



A.10 Do you get to go to the religious services you want?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

A.11 What other kinds of things do you like to do? (SPECIFY)

A.12 Can you do these things when you want?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

B. ADL/IADL QUESTIONS

This set of questions have to do with some everyday activities, like getting dressed or taking a bath. Some people have no problem doing these things by themselves. Other people have somebody to help them. For example, someone may help them with zippers or buttons, or remind them to get dressed. If you do not remember if you receive help, or whether you sometimes miss an everyday activity, please let me know.

B.1 Does anyone help you to take a bath, shower, or wash your hair? (SPECIFY)

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Receives Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 ☐ RECEIVES HELP FROM ANOTHER PERSON
- 2 ☐ DOES NOT RECIEVE HELP FROM ANOTHER PERSON →Skip to Q.B 5
- 97 ☐ UNCLEAR RESPONSE→Skip to Q. B 5
- 98 ☐ NO REPONSE→Skip to Q. B 5
- 99 ☐ I DON'T REMEMBER→Skip to Q. B 5

B.2 Does anyone ever make you shower or take a bath when you are not ready?

- 1 ☐ YES
- 2 ☐ NO
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

B.3 Do you sometimes not get a bath or shower when you need one?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q. B 5
- 96 ☐ UNSURE →Skip to Q. B 5
- 97 ☐ UNCLEAR RESPONSE →Skip to Q. B 5
- 98 ☐ NO RESPONSE →Skip to Q. B 5
- 99 ☐ I DON'T REMEMBER→Skip to Q. B 5



B.4 Is this because there is no-one there to help you?

- 1 ☐ YES
- 2 ☐ NO
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

B.5 Does anyone help you get dressed? (SPECIFY)

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Receives Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 ☐ RECEIVES HELP FROM ANOTHER PERSON
- 2 ☐ DOES NOT RECEIVE HELP FROM ANOTHER PERSON → Skip to Q.B 9
- 97 ☐ UNCLEAR REPONSE → Skip to Q. B 9
- 98 ☐ NO RESPONSE → Skip to Q. B 9
- 99 ☐ I DON'T REMEMBER → Skip to Q. B 9

B.6 Does anyone ever make you get dressed when you are not ready?

- 1 ☐ YES
- 2 ☐ NO
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

B.7 Are you sometimes unable to get dressed when you need to?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q. B 9
- 96 ☐ UNSURE →Skip to Q. B 9
- 97 ☐ UNCLEAR RESPONSE →Skip to Q. B 9
- 98 ☐ NO RESPONSE →Skip to Q. B 9
- 99 ☐ I DON'T REMEMBER→Skip to Q. B 9

B.8 Is this because there is no-one there to help you?

- 1 ☐ YES
- 2 ☐ NO
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

B.9 Does anyone help you get out of bed? (SPECIFY)

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Receives Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 ☐ RECEIVES HELP FROM ANOTHER PERSON
- 2 ☐ DOES NOT RECEIVE HELP FROM ANOTHER PERSON →Skip to Q.B 13
- 97 ☐ UNCLEAR REPOSE→Skip to Q. B 13
- 98 ☐ NO RESPONSE→Skip to Q. B 13
- 99 ☐ I DON'T REMEMBER→Skip to Q. B 13



B.10 Does anyone ever make you get in or out of bed when you are not ready?

- 1 ☐ YES
- 2 ☐ NO
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

B.11 Are you sometimes unable to get out of bed when you need to?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q. B 13
- 96 ☐ UNSURE →Skip to Q. B 13
- 97 ☐ UNCLEAR RESPONSE →Skip to Q. B 13
- 98 ☐ NO RESPONSE →Skip to Q. B 13
- 99 ☐ I DON'T REMEMBER →Skip to Q. B 13

B.12 Is this because there is no-one there to help you?

- 1 ☐ YES
- 2 ☐ NO
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

B.13 Does anyone help you to eat? (SPECIFY)

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Receives Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 ☐ RECEIVES HELP FROM ANOTHER PERSON
2 ☐ DOES NOT RECEIVE HELP FROM ANOTHER PERSON → Skip to Q.B 18
97 ☐ UNCLEAR RESPONSE → Skip to Q. B 18
98 ☐ NO RESPONSE → Skip to Q. B 18
99 ☐ I DON'T REMEMBER → Skip to Q. B 18

B.14 Does anyone ever make you eat when you are not ready?

- 1 ☐ YES
2 ☐ NO
96 ☐ UNSURE
97 ☐ UNCLEAR RESPONSE
98 ☐ NO RESPONSE
99 ☐ I DON'T REMEMBER

B.15 Who chooses what you eat?

- 1 ☐ I DO OR I HELP
2 ☐ NO CHOICE, SPECIAL DIET/TUBE FED
3 ☐ SOMEONE ELSE
96 ☐ UNSURE
97 ☐ UNCLEAR RESPONSE
98 ☐ NO RESPONSE
99 ☐ I DON'T REMEMBER



B.16 Are you sometimes unable to eat when you need to?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q.B 18
- 96 ☐ UNSURE →Skip to Q. B 18
- 97 ☐ UNCLEAR RESPONSE →Skip to Q. B 18
- 98 ☐ NO RESPONSE →Skip to Q. B 18
- 99 ☐ I DON'T REMEMBER→Skip to Q. B 18

B.17 Is this because there is no-one there to help you?

- 1 ☐ YES
- 2 ☐ NO
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

B.18 Does anyone help you make your meals? (SPECIFY)

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Receives Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 ☐ RECEIVES HELP FROM ANOTHER PERSON
- 2 ☐ DOES NOT RECEIVE HELP FROM ANOTHER PERSON →Skip to Q.B 21
- 95 ☐ NOT APPLICABLE, TUBE FED→Skip to Q. B 25
- 97 ☐ UNCLEAR REPOSE→Skip to Q. B 21
- 98 ☐ NO RESPONSE→Skip to Q. B 21
- 99 ☐ I DON'T REMEMBER→Skip to Q. B 21

B.19 Are you sometimes unable to get a meal when you need one?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q. B 21
- 96 ☐ UNSURE →Skip to Q. B 21
- 97 ☐ UNCLEAR RESPONSE →Skip to Q. B 21
- 98 ☐ NO RESPONSE →Skip to Q. B 21
- 99 ☐ I DON'T REMEMBER→Skip to Q. B 21

B.20 Is this because there is no-one there to help you?

- 1 ☐ YES
- 2 ☐ NO
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

B.21 Does anyone help you shop for groceries? (SPECIFY)

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Receives Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 ☐ RECEIVES HELP FROM ANOTHER PERSON
- 2 ☐ DOES NOT RECEIVE HELP FROM ANOTHER PERSON →Skip to Q.B 25
- 97 ☐ UNCLEAR REPOSE→Skip to Q. B 25
- 98 ☐ NO RESPONSE→Skip to Q. B 25
- 99 ☐ I DON'T REMEMBER→Skip to Q. B 25



B.22 Who chooses the groceries you get?

- 1 ☐ I DO OR I HELP
- 2 ☐ NO CHOICE, DIETARY RESTRICTIONS
- 3 ☐ SOMEONE ELSE
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

B.23 Are you sometimes unable to get groceries when you need them?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q. B 25
- 96 ☐ UNSURE →Skip to Q. B 25
- 97 ☐ UNCLEAR RESPONSE →Skip to Q. B 25
- 98 ☐ NO RESPONSE →Skip to Q. B 25
- 99 ☐ I DON'T REMEMBER→Skip to Q. B 25

B.24 Is this because there is no-one there to help you?

- 1 ☐ YES
- 2 ☐ NO
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

B.25 Does anyone help you with your housework or yardwork? (SPECIFY)

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Receives Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 ☐ RECEIVES HELP FROM ANOTHER PERSON
- 2 ☐ DOES NOT RECEIVE HELP FROM ANOTHER PERSON →Skip to Q.B 28
- 97 ☐ UNCLEAR REPONSE→Skip to Q. B 28
- 98 ☐ NO RESPONSE→Skip to Q. B 28
- 99 ☐ I DON'T REMEMBER→Skip to Q. B 28

B.26 Does your housework or yardwork not get done sometimes?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q. B 28
- 96 ☐ UNSURE →Skip to Q. B 28
- 97 ☐ UNCLEAR RESPONSE →Skip to Q. B 28
- 98 ☐ NO RESPONSE →Skip to Q. B 28
- 99 ☐ I DON'T REMEMBER→Skip to Q. B 28

B.27 Is this because there is no-one there to help you?

- 1 ☐ YES
- 2 ☐ NO
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER



B.28 Does anyone help you with your laundry?

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Receives Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 ☐ RECEIVES HELP FROM ANOTHER PERSON
- 2 ☐ DOES NOT RECEIVE HELP FROM ANOTHER PERSON →Skip to Q.B 31
- 97 ☐ UNCLEAR RESPONSE→Skip to Q. B 31
- 98 ☐ NO RESPONSE→Skip to Q. B 31
- 99 ☐ I DON'T REMEMBER→Skip to Q. B 31

B.29 Does your laundry not get done sometimes?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q. B 31
- 96 ☐ UNSURE →Skip to Q. B 31
- 97 ☐ UNCLEAR RESPONSE →Skip to Q. B 31
- 98 ☐ NO RESPONSE →Skip to Q. B 31
- 99 ☐ I DON'T REMEMBER→Skip to Q. B 31

B.30 Is this because there is no-one there to help you?

- 1 ☐ YES
- 2 ☐ NO
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER

B.31 Does anyone help you take medicine, such as remind you or set up your doses? (SPECIFY)

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Receives Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 ☐ RECEIVES HELP FROM ANOTHER PERSON
- 2 ☐ DOES NOT RECEIVE HELP FROM ANOTHER PERSON → Skip to Q.B 34
- 95 ☐ NOT APPLICABLE - DOES NOT TAKE MEDS → Skip to Q. B 34
- 97 ☐ UNCLEAR REPOSE → Skip to Q.B 34
- 98 ☐ NO RESPONSE → Skip to Q.B 34
- 99 ☐ I DON'T REMEMBER → Skip to Q. B 34

B.32 Are you sometimes unable to take your medicine when you need it?

- 1 ☐ YES
- 2 ☐ NO → Skip to Q.B 34
- 96 ☐ UNSURE → Skip to Q.B 34
- 97 ☐ UNCLEAR RESPONSE → Skip to Q.B 34
- 98 ☐ NO RESPONSE → Skip to Q.B 34
- 99 ☐ I DON'T REMEMBER → Skip to Q.B 34

B.33 Is this because there is no-one there to help you?

- 1 ☐ YES
- 2 ☐ NO
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER



B.34 Does anyone help you manage your money?

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Receives Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 ☐ RECEIVES HELP FROM ANOTHER PERSON
2 ☐ DOES NOT RECEIVE HELP FROM ANOTHER PERSON →Skip to Q.B 36
97 ☐ UNCLEAR REPONSE→Skip to Q. B 36
98 ☐ NO RESPONSE→Skip to Q. B 36
99 ☐ I DON'T REMEMBER→Skip to Q. B 36

B.35 Are you sometimes unable to get the help you need to manage your money?

- 1 ☐ YES
2 ☐ NO
96 ☐ UNSURE
97 ☐ UNCLEAR RESPONSE
98 ☐ NO RESPONSE
99 ☐ I DON'T REMEMBER

B.36 Does anyone help you get to and use the bathroom? (SPECIFY)

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Receives Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 ☐ RECEIVES HELP FROM ANOTHER PERSON
2 ☐ DOES NOT RECEIVE HELP FROM ANOTHER PERSON →Skip to 53
97 ☐ UNCLEAR REPONSE→Skip to 53
98 ☐ NO RESPONSE→Skip to 53
99 ☐ I DON'T REMEMBER→Skip to 53

B.37 Are you ever unable to get to or use the bathroom when you need to?

- 1 ☐ YES
- 2 ☐ NO →Skip to 53
- 96 ☐ UNSURE →Skip to 53
- 97 ☐ UNCLEAR RESPONSE →Skip to 53
- 98 ☐ NO RESPONSE →Skip to 53
- 99 ☐ I DON'T REMEMBER→Skip to 53

B.38 Is this because there is no-one there to help you?

- 1 ☐ YES
- 2 ☐ NO
- 96 ☐ UNSURE
- 97 ☐ UNCLEAR RESPONSE
- 98 ☐ NO RESPONSE
- 99 ☐ I DON'T REMEMBER



V. CLOSING AND INTERVIEWER COMMENTS

53. Is there anything else you want to talk to me about?
(RECORD RESPONSE IF FOLLOW-UP IS NEEDED)

Thank you for talking with me today. I really appreciate all your help. If you need to talk to me again or have other questions, here is how you can reach me. INFORMAL PARTING OF YOUR CHOICE – GOOD-BYE, TAKE CARE, HANDSHAKE, ETC.

FOR THE INTERVIEWER ONLY

What amount of the questions did the program participant answer by him/herself?

- ☐ ALL
- ☐ MOST
- ☐ ABOUT HALF
- ☐ SOME
- ☐ A FEW
- ☐ NONE

Who else provided responses? (If applicable) _____

Other comments:
